

Community Perspectives on Autism Spectrum Disorder

Thesis

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By

Erica C Jacoby

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Ohio State University

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Thesis Committee:

Dr. Joseph Guada, Advisor

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Abstract

As rates of Autism Spectrum Disorder (ASD) continue to rise, we will see an influx of adults with ASD who are looking for housing, jobs, and access to recreational activities. Currently, we know little about how adults on the spectrum will be received by other community members when encountered in these types of community settings. Most importantly, we do not know what types of experiences lead to a more positive public attitude. The data was collected using a cross-sectional design through an in-person survey. The survey gathered information on demographics, personal experience with people with ASD, knowledge about ASD, and comfortability in response to video clips showing individuals with autistic behaviors. 88 adults (average age of 37) participated, 74 of which had heard of Autism Spectrum Disorder. Average comfortability was rated as a 6.8 on a scale of 0-10, ranging from very uncomfortable, to very comfortable. It was found that knowledge had no relationship with attitude, while personal experience did (correlation 32%, $p=.003$). This study shows us that there is room to improve the community's attitude towards adults with ASD, and provides guidance for future interventions designed to positively increase the public's attitudes.

Dedication

I dedicate this thesis to Andrew George Clark, who has provided a constant supply of motivation as this research has been performed. He has encouraged me to always pursue the best version of myself and my work.

Acknowledgements

I would like to show my gratitude, first and foremost, to my thesis mentor, Dr. Guada for all his guidance, motivation, and helpful critique. He was always available when I needed direction, and went above and beyond the expectations for a mentor. I would like to thank the College of Social Work for providing me with this opportunity, with a special “thank you” to the professors that did an amazing job teaching me the foundations of research: Dr. Maguire-Jack, and Dr. Begun. I would also like to recognize all the devotion, time, and thought that Jennie Babcock put into the undergraduate research program. Lastly, I want to thank my parents; the support that they have provided in every aspect of my schooling has been immeasurable.

Curriculum Vitae

June 2011.....Miamisburg High School

May 2015.....B.S. Social Work, Honors with Research Distinction,

Magna cum laude, The Ohio State University

Fields of Study

Major Field: Social Work

Table of Contents

Abstract.....	iv
Dedication.....	v
Acknowledgements.....	vi
Curriculum Vitae.....	vii
Chapter 1: Statement of Research Topic.....	1
Chapter 2: Literature Review	6
Chapter 3: Methodology.....	11
Chapter 4: Results.....	18
Chapter 5: Discussion.....	29
References.....	35
Appendices.....	39

List of Illustrations

Table 1: Description of the Sample.....	18
Figure 1: Frequency of Comfortability Scores.....	21
Figure 2: Frequency of Knowledge Scores.....	22
Figure 3: Frequency of Personal Experience Scores.....	24
Figure 4: Percentage of Types of Personal Experience.....	26
Figure 5: Comparison of Main Variables.....	31

Chapter 1: Statement of Research Topic

Introduction

The amount of people diagnosed with an Autism Spectrum Disorder (ASD) is becoming more prevalent with each passing year. The CDC reports that of children born in 1992, 1 in 150 had a diagnosis of ASD by the age of 8 years old; for children born in 2002, 1 in 68 had a diagnosis of ASD by the age of 8 years old (refer to appendix A). As this generation of children with ASD begins to grow older, we will see an influx of adults with ASD. These adults will be looking for housing, jobs, recreational activities, and social supports just like other adults. Experiencing negative attitudes from other community members could severely affect an adult with ASD's ability to access the same opportunities that other adults have. When community members like landlords, employers, and authority figures hold negative attitudes towards individuals with disabilities, those attitudes affect the person's ability to have equal opportunities for housing, jobs, and recreation within the community (Corrigan, 2004); all of which are important for living a fulfilling, healthy life (World Health Organization, 1997).

Studies shows that negative attitudes and stigmas are correlated with a person displaying autistic behaviors; the more extreme the behaviors, the less willing the person is to interact with the disabled individual (Butler, 2011). For an individual with autism, this is a large hurdle, as often times the physical, repetitive behaviors that accompany autism are much more profound than the person's disability when it comes to social skills and intelligence. That is, a person with ASD might repetitively flap their hands in front of their face and make odd noises, yet they are highly intelligence and are able to function well in their environment (Sue Rubin is a perfect example of this [Rubin, 2014]). The fact that behaviors that are more pronounced elicit a more negative attitude from the public means that a person with these behaviors might be at a social

disadvantage that is disproportionate to their disability, and they might be withheld from activities and opportunities that they are perfectly qualified for.

This study seeks to find what the current attitudes of adults are towards adults on the Autism Spectrum when encountered in their communities. This study will also seek to find what other variables are associated with having more positive attitudes. If we have a better understanding of public attitudes, we are better prepared to potentially influence these attitudes to a more inclusive and supportive direction.

Statement of the Problem

Autism Spectrum Disorder (ASD) currently affects 1 in 68 children in the U.S., and the rates have been continuously increasing. It is clear that autism is occurring with a higher frequency (not just that we are getting better at diagnosing) and that the rates will continue to increase, bringing forward the need to be prepared for including those with autism in our communities (What is Causing the Increase in Autism Prevalence?, 2010). ASD can affect individuals in many different ways, but generally the disorder includes difficulty in communicating both verbally and non-verbally, difficulty in picking up on social cues, and engaging in repetitive behaviors (DSM-5 Diagnostic Criteria, 2014). Often these behaviors can seem like a disinterest in socializing, but they are simply barriers created by the disorder, not a lack of social interest on the part of the individual. Because ASD was not recognized as a disorder in the DSM until 1987, and then had very sudden and rapid increases in rates, many people have incomplete or misinformed ideas about the disorder and how it affects the people that are living with it. Johns Hopkins University offers a list of ideas that are often thought about people with ASD, but that are untrue. Among this list are items such as, “children and adults

with autism spectrum disorders do not care about others,” and “people with autism spectrum disorders cannot have successful lives as contributing members of society” (Doyle, 2003).

Believing myths and stereotypes about people with ASD creates stigma, which, when we look at other groups who experience stigma due to mental illness, for example, we see that it keeps the people defined by stigma from being given the same opportunities as others (Corrigan, 2004). For people with mental illness, being a victim of public stigma can also lead to self-stigma, where-in an individual internalizes the stereotypes that they hear about themselves and will no longer attempt to attain the equal opportunities that they deserve to have (i.e. decent housing, jobs, education) (Sickel, Nabors, & Seacat, 2014).

Purpose of the Study

The purpose of the study is to explore attitudes of adults in the general community towards individuals with Autism Spectrum Disorder (ASD). Specifically, the study will look at a person’s attitude in terms of the participant’s level of comfortability in relation to encountering people who have ASD in community settings. The study is also looking to test if there is a relationship between personal experiences, knowledge about the disorder, and levels of comfortability. This study will be of cross-sectional design using an in-person survey.

The present study is exploratory by gathering information regarding levels of comfortability and personal experiences and knowledge of ASD. Previous studies have assessed people’s knowledge of ASD to represent how welcoming their attitudes will be towards their peers with ASD, but there has never been data collected to see if a relationship between knowledge and positive attitudes exist. This study seeks to test if there is such a correlation with

positive attitudes (high comfortability) and personal knowledge and experiences with individuals with ASD. This study seeks to fill an important gap in the present literature as well as provide some basic information as to what types of experiences and knowledge might be associated with higher comfortability. This information could be used in future research to further test what aspects of a person's experience and knowledge could increase comfortability towards people who have an ASD. The information can also identify the adult population's current attitude towards adults with autism, and assess whether or not there is a need to increase positive attitudes. If there is a need to increase positive public attitudes, this study can provide information on what types of interventions might lead to more positive attitudes.

Research Questions

- What attitudes are present for adults towards individuals with Autism Spectrum Disorder (ASD) when experienced on a typical day?
- Does the amount of knowledge about the disorder have an effect on a person's attitude towards an individual with ASD?
- Does the amount of previous experience with ASD have an effect on a person's attitude towards an individual with ASD?
- Does amount of previous experience with ASD have an effect on a person's knowledge about ASDs?
- Do the *types* of experiences (personal contact, media, books) have an effect on a person's attitude towards an individual with ASD?

-Do the *types* of experiences (personal contact, media, books) affect knowledge about the disorder?

-Do demographic factors affect the experiences, knowledge, or attitudes?

As this is an exploratory study, our primary goals are to simply measure and quantify the three main variables: Attitude (comfortability); Personal Experience; and Knowledge. We want to see how comfortable people are in response to experiencing adults with autism in their communities; how much personal experience they have had with people with autism; and how much they know about Autism Spectrum Disorder itself. Next, we want to see if there are any relationships existing between these variables. Mainly, we want to see whether knowledge or personal experience correlate with higher levels of comfortability.

Next, we will see if there is any relationship between the variables of personal experience and knowledge, as this will give us a further understanding of how the three main variables interact. Then, we will take a look at what specific types of personal experience might correlate with 1) higher comfortability, and 2) higher knowledge. This will provide an opportunity to ascertain whether any personal experience affects comfortability levels, or if only certain types of personal experience increase comfortability (e.g. having a close friend or family member with an ASD, images of autism in the media, etc.). Lastly, as previously noted, we will test if any demographic factors have a relationship with any of the three main variables.

Chapter 2: Literature Review

Community Inclusion for Adults with Autism

While Autism Spectrum Disorder (ASD) is considered a developmental disorder, a key category of its diagnostic criteria is that of deficits in social skills (DSM-5 Diagnostic Criteria, 2014). These deficits make it more difficult for individuals on the spectrum to initiate, build, and maintain social relationships. A qualitative analysis done through interviews with individuals on the spectrum found that some of their common experiences were feelings of social isolation, a longing for greater intimacy, and a desire to contribute to their community (Müller, 2008). Although we can see the need for those with autism to feel included, there is a deficit of research done on the current situation of inclusion of and attitude towards adults with autism in the literature. Because of this, the present review will include studies regarding Intellectual and Developmental Disabilities (IDD), as Autism Spectrum Disorder falls under the umbrella of these types of disabilities.

In 2013, Angela Novak Amado did a major study in an attempt to paint a picture of the current situation of both social inclusion and community participation for adults with IDD. The study found that adults with IDD had few people that they considered friends, and that often these friends were family members and paid staff, not general community members. The study also found that adults with IDD consistently reported higher levels of loneliness than non-disabled community members, and that adults with IDD have lower levels of community participation than both non-disabled community members, and community members with other types of disabilities (Novak Amado, 2013).

Thus, research demonstrates that adults with developmental disabilities report ongoing problems with having close friendships or actively participating in their communities. It is fair to say that adults with ASDs likely face similar challenges.

Importance of Social Inclusion and Community Access

The United Nations recognizes “full and effective participation and inclusion in society” as an essential principle in bringing forth equality for individuals with disabilities (Convention on the Rights of Persons with Disabilities, 2006). The positive effects that come from social inclusion are not just important for those with disabilities, but are recognized as being universal. In creating a scale for measuring quality of life in an individual, the World Health Organization included items such as personal relationships, social support, accessibility to social care, and opportunities for recreation (World Health Organization, 1997). We can see that having social connections as well as having access to recreational activities is an important factor in the quality of a person’s life, regardless of whether or not they have a disability.

The literature demonstrates that having a choice in what type of recreational activity one would like to participate in is especially powerful for individuals with Developmental Disabilities (DD), a diagnostic category that includes Autism Spectrum Disorders. Those who had their choice of recreational activities perceived themselves as having higher levels of emotional and physical well-being (Badia, Orgaz, Verdugo, Ullan, Martinez, 2013). We have also seen a positive association between quality of life and having friendships and access to leisure activities, specifically in the Intellectually Disabled population (ID) (Duvdevany, Arar, 2004). Again, although autism doesn’t necessarily fall under ID, 46% of individuals with autism also have an ID, thus the finding can be important for a substantial portion of those with an ASD. Additionally, another study found that adults with any disabilities who were given transportation

vouchers used them principally in order to participate in community activities as opposed to attending medical appointments or visiting family (Samuel, Lacey, Giertz, Hobden, LeRoy, 2013).

As Autism continues to be on the rise, jumping from just .8% of children to 1.4% in six years, and currently with 1 in 68 twelve-year-olds being on the spectrum (Data and Statistics, 2014), there will be a greater percentage of adults on the spectrum in the near future. As has been shown, research demonstrates that individuals living with disabilities such as DD, ID, and an ASD want to be included socially and want to take part in recreational activities. Nonetheless, it remains unclear how the broader community might respond and how this response might impact the lives of adults with ASDs living in the community.

Current Attitudes Towards ASD

Currently, there is little information on the attitudes of the general adult populations towards individuals with autism. There are studies that look at knowledge of autism as a representation for attitude towards people with autism (Tipton & Blacher, 2014; Campbell and Barger, 2011). Nonetheless, these studies are limited due to the lack of established connection between knowledge and attitude in the area of autism spectrum disorders. Other studies that have looked directly at attitude or comfortability have been done with either middle school students (Chambres, Auxiette, Vansingle, & Gil, 2008; Campbell, 2007) or with university students (Butler and Gillis, 2011; Nevill & White, 2011). While university students are of adult age, they are typically unrepresentative of the broader adult population. The present study seeks to expand the literature by doing an exploratory study of present attitudes, knowledge, and prior personal experience regarding adults with autism with a representative sample of adults living in a local community.

Although the existing research doesn't provide much information regarding adult's attitudes towards other adults with ASDs, it does hint to several interesting factors. For example, when individuals were given an explanation of autism, or simply told that the individual they were responding to had an autism disorder, they had a more positive response (Chambres, Auxiette, Vansingle, & Gil, 2008; Campbell, 2007). On the other hand, university students showed high levels of stigmatization towards individuals on the spectrum, which consistently increased as the severity of the autistic behaviors increased (Campbell, 2007).

Lastly, two of the studies demonstrate a possible connection between prior experience with autism and having either more knowledge, or a more positive attitude towards individuals with autism. In a large study of middle school students, they found that those who had "prior awareness" of autism (whether from personal experience or being taught about it) had significantly more knowledge about the characteristics of the disorder (Campbell and Barger, 2011). In a study of university students "openness" towards peers on the spectrum, they found that people who had a first-degree relative with ASD were significantly more open and comfortable with having a peer with autistic behaviors (Nevill & White, 2011). Such studies are promising and highlight the need to do similar studies with a sample from the general adult population.

Literature regarding attitudes towards those with IDD or a mental health diagnoses

It seems that there is some connection between knowledge, personal experience, and attitudes towards individuals with autism. Although the studies mentioned above suggest that variables such as knowledge, prior personal experience, and general attitudes towards individuals with autism are related to each other, it remains unclear what kinds of relationships exist within adult populations. Although not about ASD specifically, there is literature that has tested the

relationships of these variables within adult samples in regards to individuals with mental health and IDD diagnoses.

For example, many studies looked at attitudes towards people living with mental illness. While many of these studies tell us that knowledge about diagnoses and treatment can change attitudes towards people with mental illnesses (Corrigan, Rowan, Green, 2002; Morin, Rivard, Crocker, Boursier, & Caron, 2013; Morgan & Lo, 2013; Lim, Mun Wo, Ahmad, & Tan, 2013), a study that looked at the long-term effects of the gained knowledge found that the change in attitude was only temporary, and did not have a lasting effect on attitude or behavior (Corrigan, Rowan, Green, 2002). Further studies showed that personal experience not only changed attitudes, but that the change in attitude was maintained over time, unlike the change due to knowledge. It was found that within a single occurrence of personal contact, both prejudice and discrimination towards people with mental illness decreased (Pettigrew & Tropp, 2006).

In a study looking specifically at comfort levels towards individuals with Intellectual Disabilities (IDs) they found a multitude of variables that correlated with level of comfort. Variables that had a relationship with comfort levels included several demographics, such as: gender, age, level of education, and income. They also found that knowledge, quality of personal experience, and quantity of personal experience had an effect size of 5% on increasing comfort levels. The variable that showed to have the largest effect size (7%) on comfort levels towards individuals with ID was the *frequency* of personal contact that the participant had with someone with ID (Morin, Rivard, Crocker, Boursier, & Caron, 2013). This study suggests that it is not just a matter of whether or not personal experience has occurred that affects attitudes, but how often that personal interaction occurs over time.

Summary Statement

It is clear that previous literature suggests that adults with autism want to be active in the community and build intimate friendships (Müller, 2008). We can also see that inclusion in society and access to recreational activities is necessary for overall well-being (United Nations, 2006; World Health Organization, 1997). Yet, the literature also shows that adults with developmental disabilities report ongoing problems with having close friendships and actively participating in their communities (Novak Amado, 2013). College students with autism experience stigma from their peers (Campbell, 2007), but we don't know how adults with autism are received by their communities.

Past studies suggest that there might be a connection between prior personal experience with people with autism, knowledge about autism, and attitudes towards people with autism, but there have never been any studies directly assessing the relationships between these variables (Campbell and Barger, 2011; Nevill & White, 2011). Studies done about other stigmatized groups with mental illness found that gaining knowledge increased positive attitudes of the public temporarily, while having any amount of personal experience with the stigmatized individual increased positive attitude and decreased discrimination long-term (Corrigan, Rowan, Green, 2002; Pettigrew & Tropp, 2006).

Chapter 3: Methodology

Research Design

This is an exploratory study of cross-sectional design using an in-person survey. The survey was created and hosted on the Qualtrics secure website. The survey consisted of 4 sections: 1) Demographics 2) Personal Experience with Individuals with Autism Spectrum Disorder (ASD) 3) Knowledge About ASD; and 4) Comfortability Towards Individuals with

ASD. The responses to the questions in sections 1-3 were multiple choice, true or false, or check-all-that-apply; with exception to the question for participant's age, which was a fill-in answer. For the aforementioned Comfortability section, participants responded using a Likert scale of 0-10.

Data Collection Procedures

The authors received approval from the Institutional Review Board of The Ohio State University to perform this study. Approval was also sought and received from the City of Columbus to perform data collection in their public parks and in front of libraries. In an attempt to reach a diverse population, the author used public census information about the neighborhoods of Columbus to decide which park and library locations would be used for data collection.

The survey used for this study is hosted on the secure site of Qualtrics. The survey was accessed through iPads, provided to participants by the author and key personnel. The author and key personnel would visit one park or library location at a time, during peak hours, and approach any person who appeared to be above the age of 18, and not occupied with any other activity. Potential participants were first asked if they would be interested in taking a short survey about community perspectives towards Autism Spectrum Disorder, and if they were interested, they were given more information about the survey. If participants still wanted to take the survey they were handed the iPad and offered a stylus. Participant's had the ability to skip any question, and to stop taking the survey at any time. The full recruitment dialogue used by the author can be seen in appendix B.

The first page of the survey contains the consent form, which was also offered in print to participants. Participants took the survey independently, although the author and key personnel

remained nearby to answer any questions and assist with the technology if needed. There was no follow-up with participants after completing the survey and no identifying information was collected.

Measures

Due to the lack of previous tools existing for surveying an adult population about attitudes towards adults with ASD, the author created an original survey. The survey was built around knowledge and information about the ASD community from a variety of resources. Each variable being studied (personal experience, knowledge, comfortability) was designed in a way as to be quantifiable so that participants had a final “score” for each variable. The sections for each variable were designed as follows:

Personal Experience

The first question of this section simply states “Have you heard of Autism Spectrum Disorder?”. Participants chose an answer of “yes”, “no”, or “I’m not sure”. If “no” was answered then the survey automatically bypassed the section on personal experience with a person with ASD for that participant and took them directly to the section on knowledge. Participants who answered “no” were given a score of 0 for personal experience. If participant’s answered “yes”, “I’m not sure”, or did not provide an answer, they were taken to the page of the survey with questions about personal experience with individuals with ASD.

The personal experience section of the survey has four questions in total, one of which is check-all-that-apply, and three of which are multiple choice. Based on a study done by Morin, Rivard, Crocker, Boursier, and Caron (2013), there is a distinction between the amount of personal experience a person has, and the type of personal experience someone has in terms of

how much a person's attitude is affected by experience. The questions for this study aimed to ascertain both amount and the type of personal experience. The four questions used are as follows: "Where have you heard of Autism Spectrum Disorder?" (type of experience); "How many different individuals have you encountered with Autism Spectrum Disorder? This can include acquaintances, a character on a TV show, etc." (quantity of experience); "About how many years ago did you first hear about Autism Spectrum Disorder?" (quantity of experience); and "How would you rate your past interactions with people with Autism Spectrum Disorder?" (type of experience).

Knowledge

This section of the survey was presented to all participants. They were asked to answer the questions using their personal knowledge of autism. This section consists of 8 questions overall, four of which are multiple choice, two of which are true or false, and two of which are check-all-that-apply. Several of the questions were based on DSM 5 information about behaviors and social patterns used for diagnosing individuals with ASD (DSM-5 Diagnostic Criteria, 2014). Several of the questions were inspired by the page of "Myths and Facts" about autism, presented by John Hopkins University, which addresses myths that the public has been known to have about individuals with ASD (Doyle, 2003). Lastly, questions were informed by general information about ASD presented by the CDC (Data & Statistics, 2014).

All questions have one possible correct answer, with all others answers being incorrect (the check-all-that-apply questions were either correct or incorrect in terms of whether or not they should be checked). Some questions have a "most" correct answer, with some of the "incorrect" options being possibly correct in certain scenarios, but not being the most correct answer at all times.

Comfortability

This section consists of three short video clips and ten Likert scale questions. The video clips each show a different adult on the Autism Spectrum. The clips were found on YouTube and chosen for their succinct portrayals of an adult who has observable autistic behaviors. The three individuals shown were also chosen because of how different they are from one another, so as to show participants a variety of individuals with autism.

After viewing a video clip, participants were asked how comfortable they would be interacting with the individual shown in the video in a variety of settings. There are three to four questions per video/individual shown. Participants chose how comfortable they would be on a scale of one to ten, with one being “very uncomfortable,” five being “neither uncomfortable nor comfortable” and ten being “very comfortable”. The settings vary from social to professional, and also vary in levels of intimacy. An example of a question that is social with low intimacy is “How comfortable would you be having Roy in a recreational club with you, like a book club or fitness class?”. An example of a question that is professional with high intimacy is “How comfortable would you be having Tracee as a coworker?”

The scenarios that were chosen to go with each video clip were based on the perceived level of functioning of the individual shown; therefore the individual that has the question “How comfortable would you be having Tracee as your doctor” shows high cognitive function and could potentially be a doctor. All of the scenarios, from social to professional, were inspired by the multitude of existing vocational, occupational, and recreational programs for adults with autism that are working to get adults on the spectrum out into the communities. These programs often place individuals in jobs such as those mentioned in this survey (e.g. waiting tables, being a cashier). There are also many programs supporting individuals on the spectrum who want to go

to college to seek higher level jobs (e.g. doctors, working in a business office). There are also a number of programs that support individuals with ASD who want to have access to openly live and play in their greater communities, without having to be segregated to being with only other individuals with disabilities. Therefore, the scenarios presented in this survey are not simply hypothetical; they are expected to be realities of where we will begin to see adults with ASD out in communities as these programs continue to grow.

Informal Pilot Survey

Once the survey tool had been finalized, it was sent out to a convenience sample using social media. 45 people participated in the pilot survey, which included taking the survey itself, and also giving write-in feedback for each section of the survey. The author used this information to correct unclear language, adjust the “flow” of the tool, and to test face validity. After making minor adjustments from the feedback of the pilot survey, the final version of the survey was created and used for data collection. The final survey is found in appendix D.

Data Analysis

The data was exported from Qualtrics to Excel in both raw form, and a form provided by Qualtrics that reports all frequencies and central tendencies for individual questions. The data was cleaned for missing responses, including one data point in which the participant had reported their demographics, but not filled out any more information. As this study was exploratory in nature, the primary statistical analyses were that of central tendency as well as overall frequencies and standard deviations. The relationships between several of the variables were

also analyzed using the Pearson's Bivariate Correlation Matrix. The author used a .05 correlation level to determine significance.

Chapter 4: Results

Demographics of the Sample

Participants consisted of adults who were approached by the main researcher in parks and libraries within Columbus, Ohio, and who then agreed to participate in the study. All participants first gave informed consent, and then independently took the survey on an iPad provided by the researcher. The sample collected consisted of 88 participants, with an age range of 21-69, and an average age of 37. The sample was mostly Caucasian (83%), followed by African American (8%), and Latino (7%). The sample was split almost equally between males (57%) and females (43%). Most participants had either a college degree (41%) or graduate degree (27%). Complete demographics are shown in the table below.

TABLE 1. Description of the Sample

Variable	N	Range	Mean±SD
Age	88	21-69	37.6±13.6
Variable	N	Percentage	
Gender			
Male	50	57%	
Female	38	43%	
Ethnicity			
White or Caucasian	73	83%	
Black or African American	7	8%	
Hispanic or Latino	6	7%	
Native American or American Indian	2	2%	

Asian/Pacific Islander	2	2%
Other	2	2%
<i>Highest Education Level Completed</i>		
No schooling	0	0%
High school graduate or GED	9	10%
Some college	36	41%
Graduate degree	24	27%
<i>Residential Type Most Lived In</i>		
Urban Type	41	47%
Suburban Type	41	47%
Rural Type	6	7%
<i>Estimated Average Annual Household Income</i>		
23,000-	16	18%
23,000-32,500	3	3%
32,500-60,000	25	29%
60,000-100,000	18	21%
100,000+	25	29%

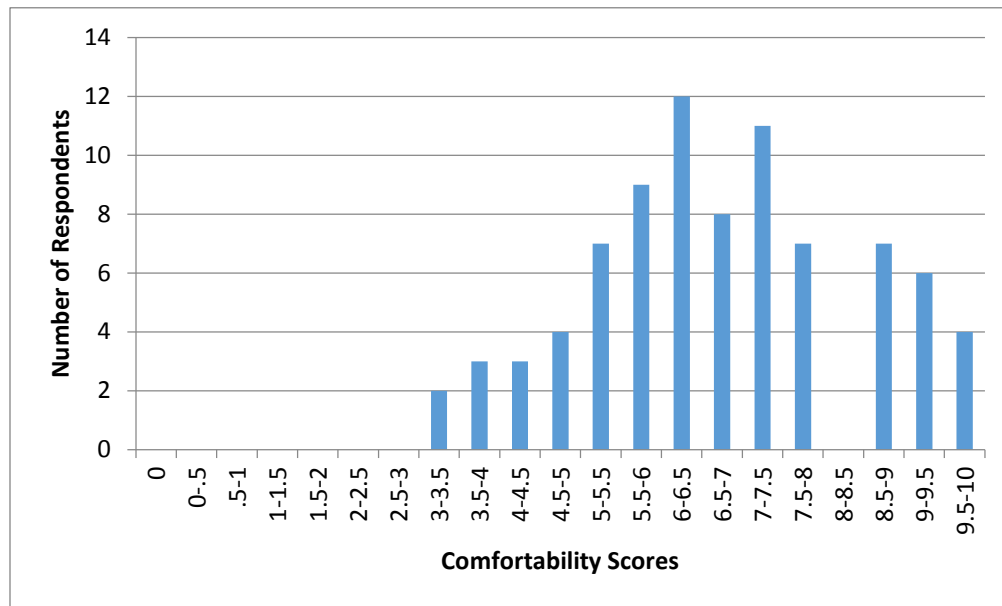
Research Q. 1: What attitudes are present for adults towards individuals with Autism Spectrum Disorder (ASD) when experienced on a typical day?

Participants were asked to rate comfortability on a scale of 0-10, using whole integers, with 0 described as “very uncomfortable,” 5 as “neither uncomfortable or comfortable,” and 10 as “very comfortable.” There were 10 questions of comfortability over all, each described within a different setting within the community, with varying levels of intimacy. All questions of comfortability fit into a category of either social environment or professional environment. There was notable attrition (16%) during the questions of comfortability, which included watching a short video less than 1 minute in length, to answer these items. It is possible that participants did not want to take the time to watch the videos involved with the comfortability questions. Although the number of responses varied throughout the questions of comfortability, on average, 77 responses were collected for each question.

The sample’s overall rating of comfortability on the scale of 0-10 was 6.77 (SD=1.65). In environments of social situations (e.g. going out to eat, participating in recreational clubs, having mutual friends, and being next-door neighbors) the average comfortability score was 6.97 (SD=1.28). In environments of professional situations (e.g. the individual with ASD being the participant’s cashier, waiter, co-worker, or doctor) average comfortability was 6.60 (SD=1.33). The item with the highest comfortability rating was: “How comfortable would you be having Roy as your next-door neighbor?”; the average response was an 8.71 (SD=1.53). This question is a part of the social category, with a high level of intimacy. The item with the lowest comfortability rating was the item asking “how comfortable would you be having Tracee as your doctor?”; the average response was a 4.82 (SD=2.79). This question is part of the professional

category, with a high level of intimacy. A graph displaying the frequency of comfortability scores is shown below.

FIGURE 1. Frequency of Comfortability Scores

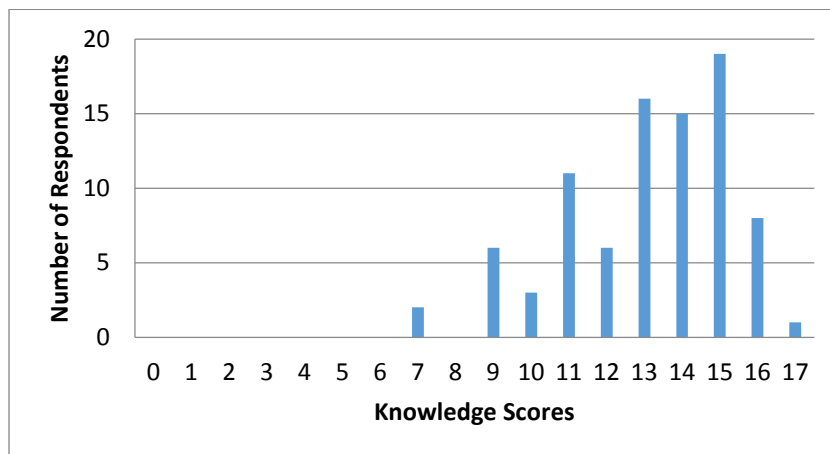


Research Q. 2: Does the amount of knowledge about the disorder have an effect on a person's attitude towards an individual with ASD?

To answer this question we first quantified the knowledge section from the survey tool and gave each participant a “knowledge score”. All items from the knowledge section had at least one right answer, and multiple incorrect answers. Participants were given a score of 1 for each correct response, and 0 for each incorrect response. Participants could score any value between 0 and 17. While only one participant answered every item correctly (value of 17), the results were strongly skewed to the right, showing that the general adult population of this sample had above average levels of knowledge (see FIGURE 2 below).

The average score for the knowledge section was 13.09 (SD=2.22). The item with the highest rate of correct responses (94%) was item #12, “When is Autism Spectrum Disorder thought to start developing?”. The item with the lowest rate of correct responses (32%) was item #19, “‘Savant’ skills are a symptom of autism, meaning that individuals with autism are extremely skilled in one specific area, and lacking skills in all others”. It is possible that this item was especially confusing to respondents as Savant skills happen more frequently in individuals with autism than within the general population (although it is still rare for those with autism). A graph displaying the frequency of knowledge scores is shown below.

FIGURE 2. Frequency of Knowledge Scores



The other variable used to answer this research question was the overall “comfortability score” that participants received from the first research question. This score is between zero and ten. The average comfortability score is 6.77 (SD=1.65). The lowest score from an individual is 3.5, and the highest is 10.

The two variables for this research questions were then tested together using the Pearson's Bivariate Correlation Coefficient Matrix. A correlation of 11% was found, with significance of .34. This shows that there was no significant relationship between knowledge of autism and comfortability towards individuals with autism.

Research Q. 3: Does the amount of previous experience with ASD have an effect on a person's attitude towards an individual with ASD?

To answer this question, the author sought to compare total scores of personal experience and comfortability with each other to see if a relationship exists. First we used participant's sum comfortability score as explained in Research Question 1.

Next we quantified the section on personal experience. Respondents were first asked if they had heard of Autism Spectrum Disorder. If they answered "no" then they were given a score of zero for the personal experience section, and sent to the section of the survey on knowledge of autism. If participant's responded "yes", "I'm not sure", or did not respond they were sent to the full section on personal experience and asked further questions about their experiences. Participants were first asked "Where have you heard of Autism Spectrum Disorder?" and asked to respond in a check-all-that apply format. There were eight possible responses that participants could select.

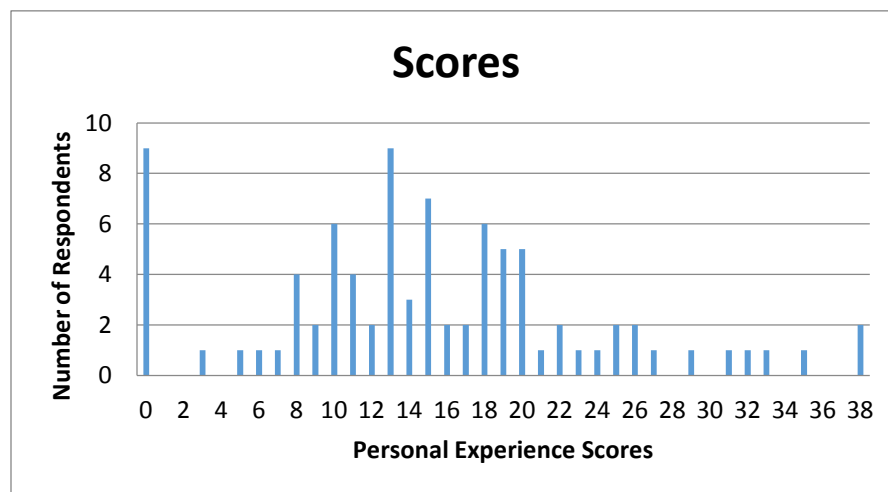
In quantifying this question the eight items were put in order and given a corresponding score on how intimate the experience was. For example, selecting "I have heard about autism through word-of-mouth" gave you a score of 1, while selecting "I am diagnosed with autism" gave you a score of 8. As a person could select multiple experiences, their scores on this item are a sum of the scores from all the experiences they have checked. The next question asked

“How many different individuals have you encountered with Autism Spectrum Disorder? This can include acquaintances, a character on a TV show, etc.” This was a multiple choice question, with six possible answers ranging from “I have never met anyone with autism” to “10+”.

Possible scores for this question ranged from zero to six. The final question used to quantify personal experience was “About how many years ago did you first hear about Autism Spectrum Disorder?” This was a multiple choice question with answers ranging from “In the last year” to “10+ years ago”.

Possible scores for this section ranged from zero to 47. The average score is 15 (SD=8.77). The highest score received was a 38, and the lowest is zero. A graph displaying the frequency of these scores is shown below.

FIGURE 3. Frequency of Personal Experience Scores



Participants overall personal experience scores and comfortability scores were then compared using Pearson’s Bivariate Correlation Coefficient Matrix. A correlation of 32% was found with a significance of .003.

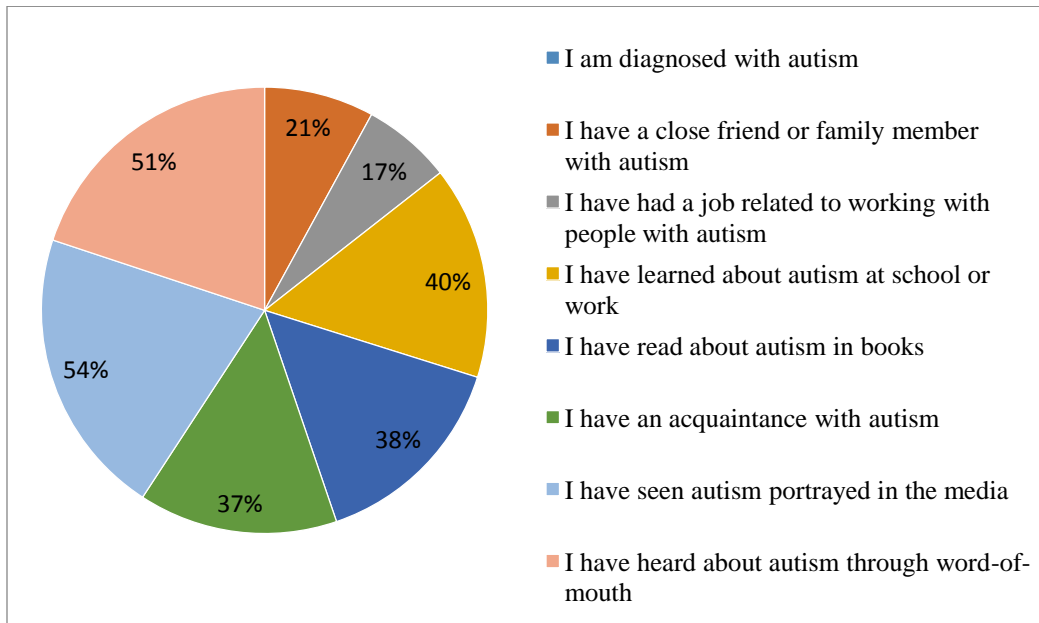
Research Q. 4: Does amount of previous experience with (a person with) ASD have an effect on a person's knowledge about ASDs?

This study sought to find if the amount of prior personal experience with an individual with ASD might be related to the amount of knowledge that an individual has about ASD. To test this idea we first took the personal experience scores as quantified in research question 3. Secondly, we used the knowledge score as quantified in research question 2. A Pearson's Bivariate Correlation was used to compare the two variables. The correlation 29% ($p = .006$) was found.

Research Q. 5: Do the types of experiences have an effect on a person's attitude towards an individual with ASD?

To answer this question, we looked at the information from item #8 on the survey tool. Participants were asked "Where have you heard of Autism Spectrum Disorder" and responded in a check-all-that-apply format. To quantify this question the eight possible responses were put in order and given a corresponding score on how intimate the experience was. For example, selecting "I have heard about autism through word-of-mouth" gave a score of 1, while selecting "I am diagnosed with autism" gave a score of 8. As a person could select multiple experiences, their scores are a sum of all the experiences they have checked. The person with the highest score on this item had a score of 28, and had selected seven of the items, with the only item they did not select being "I am diagnosed with autism". The experience with the most responses was "I have seen autism portrayed in the media" at 54% of respondents checking this box. The experience with the least responses was "I am diagnosed with autism" which zero participants checking it off. The full list of possible responses and the amount that they were selected is shown in the FIGURE 4 below.

FIGURE 4. Percentages of Types of Personal Experience



To answer this question we also used the comfortability scores, as calculated in the results of the first research question. The responses from item #8 on the survey were each independently compared to the participant's comfortability scores using the Pearson's Bivariate Correlation Coefficient Matrix.

Two experiences showed significant correlations: participants who answered "I have learned about autism at school or work" had a 27% ($p=.01$) correlation with having higher comfortability. Additionally, participants who answered "I have had a job related to working with people with autism" had a 28% ($p=.01$) correlation with having higher comfortability.

Because both items pertain to the work environment, the author tested the relationship between these two responses. A significant correlation of 25% ($p=.02$) was found. Thus, it is possible that the two items may share some variance with the comfortability variable.

Research Q. 6: Do the *types* of experiences (personal contact, media, books) affect knowledge about the disorder?

To answer this question, we again looked at the responses to item #8 on the survey tool. Participants were asked “Where have you heard of Autism Spectrum Disorder” and responded in a check-all-that-apply format. Knowledge scores as derived in research question 2 were also used for the research question. As stated above, the average knowledge score is 13 (SD=2.22) and scores ranged from 7 to 17.

The responses from item #8 on the survey were each independently compared to the participant’s knowledge scores. Several types of experiences demonstrated a significant relationship with higher knowledge scores: 1) “I have heard of autism through word-of-mouth” had a 22% correlation ($p=.04$); 2) “I have seen autism portrayed in the media” had a 25% correlation ($p=.02$); and 3) “I have read about autism in books” had a 39% correlation ($p=.0002$).

Research Q. 7: Do demographic factors affect the experiences, knowledge, or attitudes?

There were no significant findings when comparing any of the demographic factors to comfortability scores. On the section of knowledge, we found that three demographic items positively correlated with a higher knowledge score. These items and their correlation to higher knowledge are as follows: 1) being a female: 22% correlation ($p=.05$); 2) higher education: 33% correlation ($p=.002$); 3) higher income: 31% ($p=.003$). Additionally, higher education was correlated to higher income with a 36% correlation ($p=.0005$).

On the section of personal experience, there were two demographic factors that positively correlated with higher levels of personal experience. Firstly, having higher levels of education

had a correlation of 28% ($p=.009$) with having more personal experience. Secondly, being Caucasian had a correlation of 25% ($p=.02$) with having more personal experience.

Chapter 5: Discussion

Summary of the Results

As rates of Autism Spectrum Disorder (ASD) continue to increase, we will see an influx of adults on the Autism Spectrum participating in the general community. This study sought to explore the general adult community's attitudes towards experiencing adults with autism in daily, community settings. This study also sought to find if there was any relationship between knowledge about autism, personal experience with individuals with autism, and attitude towards adults with autism. For this study, comfortability towards experiencing adults with autism was used as a proxy for attitudes towards adults with autism.

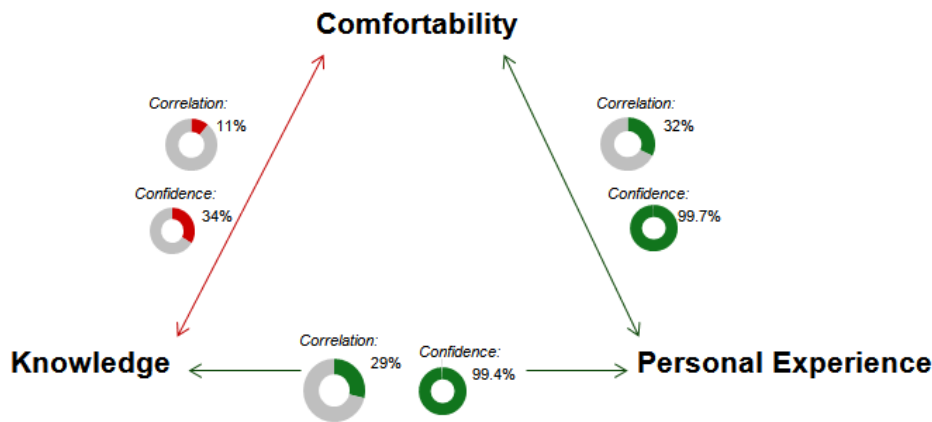
In exploring the community's attitudes towards adults with autism, the authors found that comfortability for the community is relatively high. The average answer was in the range between "neither uncomfortable nor comfortable" and "very comfortable", although the average response settled closer to "neither uncomfortable nor comfortable". This shows that at least for this sample of adults, the community should be reasonably accepting of people with autism in their communities, but also that there is room for comfortability to increase. It is possible that people reported higher comfortability in response to being presented videos of people with autism than they would when experiencing a stranger with autism in their community. This is due to the fact that people seem to have more positive attitudes towards individuals with autism when they are told that the person has a diagnosis of autism, versus experiencing them randomly and not knowing that they have an Autism Spectrum diagnosis (Chambres, Auxiette, Vansingle, & Gil, 2008; Campbell, 2007).

The results show that there is no relationship between having knowledge about autism, and comfortability levels towards experiencing people with autism. This suggests that simply telling people facts about autism, such as in “1 in 68 children are on the Autism Spectrum,” or “this is the DSM diagnostic criteria for autism” will not increase their comfortability when they run into a stranger with autism

The study did find a relationship between personal experience with people with ASDs, and comfortability levels. The relationship was positive: that is, the more personal experience a person has, the more likely they are to report higher levels of comfortability. This suggests that the more often adults can have ongoing contact with someone with ASD the more likely they will feel comfortable with interacting with them. This seems to support studies that showed similar findings for people with a mental illness (Pettigrew & Tropp, 2006; Morin, Rivard, Crocker, Boursier, & Caron, 2013).

Lastly, the author found a significant, positive relationship between personal experience and knowledge. This suggests that people who have more personal experience with people with ASDs will also have more knowledge about ASD. Thus, when comparing the three variables we see that having personal experience likely leads to an increase in both knowledge and comfortability. It is clear that the key “ingredient” here is personal experience. A visual display of the three variables and their relationships is shown below.

FIGURE 5. Comparison of Main Variables



Further analyses of the types of personal experience showed us that certain types of experiences have more of an effect on knowledge, while certain types of experiences have more of an effect on attitudes. It seemed that less intimate types of personal experiences with autism (hearing about it through word-of-mouth, seeing it in the media, and reading about it in books) led to higher knowledge. This might be due to the fact that the type of knowledge tested in this survey was very fact-based such as the type of information that would be spread through public service announcements or educational material. The two types of personal experiences that related to higher comfortability (having a job working with people autism, and learning about autism at school or work) both seemed to be based in professional environments. A possible explanation for this might be that the people who to go into jobs and schooling related to autism are the people with pre-existing positive attitudes towards people with autism.

Several demographics showed to have significant relationships with knowledge and personal experience, but there were no demographics relating to comfortability. Higher income, higher education, and being a female related to having more knowledge about autism. Having higher education and identifying as Caucasian related to having more personal experience with

autism. It is interesting that being Caucasian would relate to having more personal experience with autism, as autism occurs almost equally among ethnicities (Williams, Matson, Beighley, & Konst, 2015). One reason that Caucasians might have more exposure to autism is simply because minorities have less access to healthcare in general in the United States (Agency for Healthcare Research and Quality, 2014) which is thought to cause minority families to be less likely to receive a diagnosis for their children, or to receive those diagnoses later in the child's life (Williams, Matson, Beighley, & Konst, 2015).

Limitations

Due to the cross-sectional design of the study, this study can only point to correlations between the variables, rather than causation. Although the survey used was based on previous literature and information, the tool has not been tested for reliability or validity, except that of face validity. It is also possible that on the comfortability section of the survey participants may have demonstrated response bias by answering more positively than their actual feelings or opinions. During data collection, it was observed by the researcher that some participants did not realize the term "Autism Spectrum Disorder" (as was used in the question "Have you heard of Autism Spectrum Disorder?") was the same thing as "autism". It is possible that the accuracy of participants' answers were affected by this misunderstanding. This study was limited due to its small sample size; there was a lack of diversity within the demographics in representing the greater population of the city from which the sample was taken.

Implications

The findings in this study have implications for the future of public interventions in raising awareness of people who have Autism Spectrum Disorders. First off, we can see that

there is a need for an intervention that will increase the public's comfortability towards adults with autism in their communities. This study also gives us information on types of interventions might work best. We can see that simply increasing the public's knowledge about autism will not necessarily improve comfortability. A more effective campaign would be one that focuses on giving the public a feeling of a personal connection. This type of personal connection doesn't have to be one that's face-to-face; we can convey feelings of "meeting" a person with autism through things such as books, television shows, and even advertisements. Nonetheless, the study does suggest that one strategy that can increase overall comfortability is interacting with people with ASDs. Thus, programs designed to support independent community living should be supported.

The findings also have implications for future studies done about attitudes towards people with autism. Past studies have used "knowledge" as a proxy for "attitude" in seeing how welcoming their population will be towards people with autism (Tipton & Blacher, 2014; Campbell and Barger, 2011). The present study suggests that using knowledge as a proxy for attitude may not be the best method, as the two do not exhibit a relationship, at least in this study. A better alternative for studies trying to gauge welcoming attitudes would be to measure people's personal experience instead (if measuring attitude itself is not an option). Another suggestion is to include all of the variables previously seen in the literature, including those used here, to test relationships across variables. Such a study could help clarify and/or corroborate previous findings.

Lastly, the demographic information shows us that people who identify as Caucasian are more likely to have personal experience with autism, even though autism is equally prevalent among all ethnicities. This follows the history of research that tells us that minorities tend to be

lacking sufficient healthcare, which affects them receiving proper ASD diagnoses in a timely manner (Williams, Matson, Beighley, & Konst, 2015). This finding implies that the healthcare system needs to have a focus on creating equal opportunities to and quality of healthcare for all ethnicities.

Conclusion and Future Research Recommendations

As this study was the first of its kind, and exploratory in nature, it offers new information that the author hopes can be used in future interventions, and to guide future similar studies. This study explored the knowledge, personal experience, and comfortability of a sample of adults living in several local communities, in regards to adults with autism. It was found that knowledge has no relationship with comfortability, but that personal experience does has a significant relationship with comfortability.

If future studies were to build upon this information, it is hoped that they would be able to recruit a much larger sample that represents more demographics, and also more geographical locations. Future studies should also consider testing the survey tool for both reliability and validity. Doing a study that is longitudinal in design would be able to offer more in-depth results that might be able to point at causation.

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Appendix A: CDC Statistics on Prevalence of Autism

Identified Prevalence of Autism Spectrum Disorder ADDM Network 2000-2010 Combining Data from All Sites				
Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5 – 9.9)	1 in 150
2002	1994	14	6.6 (3.3 – 10.6)	1 in 150
2004	1996	8	8.0 (4.6 – 9.8)	1 in 125
2006	1998	11	9.0 (4.2 – 12.1)	1 in 110
2008	2000	14	11.3 (4.8 – 21.2)	1 in 88
2010	2002	11	14.7 (5.7 – 21.9)	1 in 68

Appendix B: Oral Recruitment Script

“Hi, my name is <name> and I’m a student at Ohio State University. I’m doing a study on community attitudes towards Autism. Would you be willing to take a brief survey to help with the study?”

If they wish to take the survey:

“Great! The survey should take you less than ten minutes to complete, and will ask you various questions for which you will select answers from the existing options. The questions will ask you about your personal experiences and knowledge about autism, and how you would feel interacting with a person with autism in a community setting. You are free to skip over any questions that you do not wish to answer. You will take the survey on your own, but if you have any questions during the process, about the survey itself or how to use the iPad, feel free to ask me. The first page of the survey is a consent form, which requires you to be 18 years of age or older to be a part of the study. If you are of age, and agree to the terms, then you will be presented with the beginning of the survey. Thanks for your time, let me know if you have any questions!”

If they do not wish to take the survey:

“Okay! Thank you for your time.”

Appendix C: Consent Form

Dear Potential Participant,

I am a social work major at The Ohio State University. I am currently researching community perspectives on Autism Spectrum Disorder, and how personal experiences and knowledge might affect a person's comfortability in interacting with a person on the Autism Spectrum.

To participate you must:

1. Be 18 or older

The study will be conducted with an in-person survey that will be taken privately through an online survey that is hosted on a secure web page. I am asking some personal questions, including questions regarding your age, gender, and mental health diagnosis. You will not be asked for any information that would tell me who you are, and all of your answers will be anonymous.

There is a risk that your participation in this study could cause uncomfortable or negative emotions to arise. If you feel a need or desire to leave the survey, please do so at any time.

Although there may not be a direct benefit to you, participation in this study can help improve and draw attention to community inclusion for adults who have an Autism Spectrum Disorder.

This survey is totally anonymous. It will take less than ten minutes. We will work to make sure that no one sees your survey responses without approval. But, because we are using the Internet, there is a chance that someone could access your online responses without permission. In some cases, this information could be used to identify you. Your data will be protected with a code to reduce the risk that other people can view the responses.

Your participation in this questionnaire is voluntary. You have the right to refuse to answer any question on the survey. You may also withdraw from the study at any time.

If you have any additional questions, or feel you have been harmed by participation, please feel free to contact Erica Jacoby at jacoby.66@osu.edu.

Should you have any concerns about your rights or any aspects of the study, you are encouraged to contact The Ohio State University's Office of Responsible Research Practices at 614-688-4792 or 800-678-6251.

Informational Web Pages about Autism Spectrum Disorder are offered to you in the form of a printed paper. The researcher will provide you with this paper upon your request.

BY CHECKING THE BOX BELOW THAT SAYS "I AGREE," YOU ARE INDICATING THAT YOU HAVE READ AND HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS; AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

A printed version of this form is available for you to take for your records.

☐ I AGREE

☐ I DISAGREE

Appendix D: Survey Tool

Page 1 (after consenting):

Please select the answer that best applies to you:

Q1 Age:(fill-in answer)

Q2 Gender:

- ☐ Male
- ☐ Female
- ☐ Other

Q3 Ethnicity:

- ☐ White or Caucasian
- ☐ Hispanic or Latino
- ☐ Black or African American
- ☐ Native American or American Indian
- ☐ Asian/Pacific Islander
- ☐ Other

Q4 Highest Education Level Completed:

- ☐ No schooling completed
- ☐ High school graduate or GED
- ☐ Some college
- ☐ College graduate
- ☐ Graduate degree

Q5 Residential Type You Have Most Lived In:

- ☐ Urban Type
- ☐ Suburban Type
- ☐ Rural Type

Q6 Estimated Average Annual Household Income:

- ☐ 23,000-
- ☐ 23,000-32,500
- ☐ 32,500-60,000
- ☐ 60,000-100,000
- ☐ 100,000+

Page 2

Q7 Have You Heard of Autism Spectrum Disorder?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

Page 3

This section will ask about your personal experiences with Autism Spectrum Disorder. Please answer the questions to the best of your memory:

Q8 Where have you heard of Autism Spectrum Disorder?

- ☐ I am diagnosed with autism
- ☐ I have a close friend or family member with autism
- ☐ I have an acquaintance with autism
- ☐ I have seen autism portrayed in the media
- ☐ I have read about autism in books
- ☐ I have learned about autism at school or work
- ☐ I have heard about autism through word-of-mouth
- ☐ I have had a job related to working with people with autism

Q9 How many different individuals have you encountered with Autism Spectrum Disorder?

This can include acquaintances, a character on a tv show, etc.

- ☐ 1
- ☐ 2
- ☐ 3-5
- ☐ 6-9
- ☐ 10+
- ☐ I have never met anybody with Autism

Q10 About how many years ago did you first hear about Autism Spectrum Disorder?

- ☐ In the last year
- ☐ 2-4 years ago
- ☐ 5-10 years ago
- ☐ 10+ years ago

Q11 How would you rate your past interactions with people with Autism Spectrum Disorder?

- ☐ Positive
- ☐ Neutral
- ☐ Negative
- ☐ I do not know
- ☐ I have not had any personal interactions with a person with autism

Page 4

This section will assess your personal knowledge of Autism Spectrum Disorder. Please answer these questions using your own personal knowledge of autism:

Q12 When is Autism Spectrum Disorder thought to start developing?

- ☐ Before birth, in the mother's womb
- ☐ After receiving vaccines
- ☐ After an injury to the head
- ☐ After catching it from another person

Q13 What are behaviors associated with Autism Spectrum Disorder? Check all that apply:

- ☐ Flapping hands in front of face
- ☐ Rocking back and forth
- ☐ Speaking to imaginary friends
- ☐ Repeating words and phrases
- ☐ Creating violent plans aimed at peers
- ☐ Becoming distressed in the presence of loud noises

Q14 In what areas do people with Autism Spectrum Disorder tend to struggle? Check all that apply:

- ☐ Making eye contact
- ☐ Physical growth
- ☐ Forming close relationships with peers
- ☐ Verbal communication
- ☐ Expressing themselves using art

Q15 People with autism are intellectually disabled, meaning that they have below-average levels of intelligence.

- ☐ True
- ☐ False

Q16 How many children are currently thought to be on the Autism Spectrum in America?

- ☐ 1 in 32
- ☐ 1 in 68
- ☐ 1 in 127
- ☐ 1 in 415

Q17 Which of these statements is the most accurate?

- ☐ Autism is incurable and an individual's rate of development can never improve.
- ☐ Autism is incurable, but individuals can improve their rate of development through rigorous therapy.
- ☐ Autism can be cured through a combination of medication and therapy.
- ☐ Autism can be cured through a surgical operation on the brain.

Q18 All individuals with Autism Spectrum Disorder display aggressive behaviors like hitting or biting.

- ☐ True
- ☐ False

Q19 "Savant" skills are a symptom of autism, meaning that individuals with autism are extremely skilled in one specific area, and lacking skills in all others.

- ☐ True
- ☐ False

Page 5

Below are video clips showing individuals who are on the autism spectrum. Answer the questions with the individuals from the videos in mind.

Larry: <https://www.youtube.com/watch?v=s62zFelabyQ>

Q20 How comfortable would you be having Larry at the table next to you at a restaurant?

_____ Select a number 0-10

Q21 How comfortable would you be having Larry as the cashier checking you out at a store?

_____ Select a number 0-10

Q22 How comfortable would you be going to dinner in a group with Larry?

_____ Select a number 0-10

Q23 How comfortable would you be going to dinner one-on-one with Larry?

_____ Select a number 0-10

Tracee: Some people with autism are completely non-verbal, but can communicate fluently using computers. <https://www.youtube.com/watch?v=MKXw5rjoxVc>

Q24 How comfortable would you be having Tracee as a co-worker?

_____ Select a number 0-10

Q25 How comfortable would you be having a friend who is dating Tracee?

_____ Select a number 0-10

Q26 How comfortable would you be having Tracee as your doctor?

_____ Select a number 0-10

Roy: <https://www.youtube.com/watch?v=KzZsOfhy6h0>

Q27 How comfortable would you be having Roy in a recreational club with you, like a book club or fitness class?

_____ Select a number 0-10

Q28 How comfortable would you be having Roy as your waiter?

_____ Select a number 0-10

Q29 How comfortable would you be having Roy as your next-door neighbor?

_____ Select a number 0-10

We thank you for your time spent taking this survey.

Your response has been recorded.